



## Health DATA Program

Data • Advocacy • Technical Assistance

TURNING KNOWLEDGE INTO ACTION

# Introduction to Health Data Workshop Workbook

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**UCLA Center for Health Policy Research  
Health DATA Program**

**Introduction to Health Data**

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## **A. INTRODUCTION TO HEALTH DATA OVERVIEW**

### **Workshop Summary**

Introduction to Health Data is an interactive workshop that uses games, small group activities, and “localizing” data exercises to familiarize participants with data and build critical thinking skills to assess their data needs. Once data needs are identified, relevant data can be effectively obtained and applied. Technical assistance is provided by project staff to assist participants with their use of tools learned in the workshop.

### **Goal and Objectives**

#### **Goal:**

To empower participants to understand, apply and present health research data as part of their health advocacy and policy work.

#### **Objectives:**

Upon completion of this training participants will be able to:

- Determine the appropriate uses and limitations of data
- Evaluate the integrity of data
- Collect, summarize, and interpret information relevant to an issue
- Identify relevant and appropriate data and information sources
- Effectively present accurate demographic, statistical, programmatic and scientific information to professional and lay audiences

### **Overview of the Curriculum:**

The curriculum contains four modules:

- Understanding Data
- Determining the Data You Need
- Finding Data
- Presenting Data

## 1. Understanding Data

This session uses a mock game show to help you use “tools” necessary to understand and evaluate data. You’ll learn how to critique data based on the credibility, specificity, generalizability, reliability and timeliness of the data. Using these criteria will enable you to identify gaps in data available to you and to determine the appropriate uses and limitations of health data when applying it to policy advocacy or program development work.

## 2. Determining the Data You Need

This session will help you identify relevant and appropriate data needed for different audiences to advance policy or program proposals. Through exploration and discussion, you will identify stakeholders and policymakers and the data they need. These may be community residents, organizations, government agencies, businesses or others impacted by public health or public policy issues.

## 3. Finding Data

This interactive exercise teaches you to think critically about the process of finding data. As you collect, summarize, and interpret information relevant to specific public health problems, you will also encounter some of the real dilemmas that confront those seeking data; a lack of necessary resources, a lack of quality data and a lack of access to the data they need. Through this exercise you will learn to narrow a data search and create local estimates when the data you need is not available.

## 4. Presenting Data

During this session you will gain hands on experience utilizing the knowledge you have gained in a previous session on *Determining the Data You Need*. This exercise will teach you to effectively present accurate demographic, statistical, programmatic and scientific information to professional and lay audiences.

### **Technical Assistance:**

You can receive technical assistance from the Health DATA Program following today's training conference. You can request one-on-one help with the evaluation, application and presentation of health research data to specific aspects of your organization's work.

During these consultations, you can:

- Request customized data estimates from the Center for Health Policy Research, such as information from the Current Population Surveys, the National Health Interview Surveys, or the California Health Information Survey (CHIS);
- Receive advice on effective presentation of specific data; or
- Discuss how to evaluate and apply health research data to a specific program or project.

Contact the Health DATA staff at (310) 794-0983 or email us at [hdp@ucla.edu](mailto:hdp@ucla.edu), if you need technical assistance or have questions about Health DATA technical assistance.

### **Background:**

The **UCLA Center for Health Policy Research** conducts research on national, state, and local health policy issues. The research, service, and education programs of the Center emphasize a community-and population-based perspective to improve health outcomes.

The Center provides training and technical assistance through the **Health DATA**, Data, Advocacy, and Technical Assistance Program. The Health DATA (Data, Advocacy, and Technical Assistance) program was created in 1997 in response to community needs for data and the skills to use the data effectively. The Health DATA program builds the knowledge and skills of organizations to address community needs by enhancing their capacity to effectively applying data in their decision-making, planning, policy advocacy, and other activities.

The **California Health Interview Survey (CHIS)**, based at the Center, is the largest state health survey ever conducted in the United States, collecting information from 55,000 households drawn from every county in the state. CHIS provides statewide estimates for California's overall population, including important information not previously available on an array of racial/ethnic populations, and local-level estimates for counties with populations of 40,000 or more. CHIS data is used for local planning and comparisons across counties.



## B. Understanding Data

### Learning Objectives:

- Determine appropriate uses and limitations of data
- Identify and apply criteria needed to evaluate the integrity of data

### What is Data?

Data is factual information used for decision-making. Data comes in many forms. Data can be numerical like statistics or descriptive such as an individual's observations. Data generally falls into two main categories, quantitative (numbers) and qualitative (words). The most persuasive use of data combines both quantitative data and qualitative data. The Health DATA Toolkit in Appendix A includes a listing of different types of data and their definitions.

### Criteria for Evaluating Data:

There are five criteria for evaluating data:

1. Credibility
2. Specificity
3. Generalizability
4. Reliability
5. Timeliness

#### 1. Credibility – Who produced the data?

Credibility refers to the source of the data. Can you trust the research entity that produced the data?

- Who paid for, sponsored, or funded the study.
- How much of a stake does the data source have in a specific finding? What about their mission or constituents would affect their interpretation of the data? Research affiliated with or conducted by business groups, religious organizations or political organizations may have missions that influence how they conduct research and their interpretation of the data.
- What is the organization's public image or reputation for their research? Government and academic institutions are considered credible because research is conducted for the public benefit.
- Whatever the source of the data you will want to investigate the source and examine the data for bias. Is the data distorted by a particular point of view? For instance, would you trust data about the effects of smoking from a tobacco company or pro-smoking group?

## 2. **Specificity – Is the data precise for a particular population?**

Specificity refers to data that is limited to particular conditions or factors impacting a specific population.

- Research often seeks to answer specific questions. How close is the relationship between the data provided and the data you need?
- For instance, you are looking for information on the number of Vietnamese women who smoke. Statistics are available on the number of Asians who smoke and the number of women who smoke, but nothing specific on Vietnamese women smokers.
- If the data is specific to one population you may be able to “generalize” it, that is apply it to another population.

## 3. **Generalizability – Can you apply data from one population to another population?**

Generalizability refers to data on a specific population that can be used widely for other populations.

- If the study was done in North Carolina, does it also apply to people in California?
- If it was a national study, can we use the same numbers for Orange County?
- If the study looked at Latinos, is there anything particular to say about Central Americans as a distinct group?
- How much can you “generalize” data to your constituents or service population? It is important to know the “who, what, why, when and where” of the data because it will determine how closely it matches your own need for data.

Note: specificity is similar to generalizability, but specificity refers to the information collected and generalizability refers to the population.

## 4. **Reliability - How was the data collected?**

Reliability refers to the accuracy of the data. Can the data be trusted to be accurate?

- Has the research that produced the data been reproduced by other researchers? Did other research studies get the same or similar results? Research studies that result in similar data are said to “validate” or confirm the results of the other similar studies.
- How was the data collected? Was it consistent with the mission/goals of the researchers? Did the researchers adhere to ethical research methods?
- Is there some kind of bias in who will reply? Did they conduct interviews only with older persons, which will miss the most ill who can’t come to the phone (vs. letting the caregiver give information about the elder)? Did they conduct their survey in different languages if they need information about immigrants?
- You’ll want to scrutinize the methods used to produce the data and collect other studies that validate the data you want to use.

## 5. Timeliness – When was it collected?

Timeliness refers to when the research was conducted relative to the changes occurring among a population or conditions impacting the population.

- When was the study done? And how fast are changes occurring? 1 year ago? 3 years ago? > 10 years ago? (e.g., 1990 Census) Some data may be accurate over a longer period of time than others. Some are good for only a few years. For instance, the West Nile virus was a rapidly moving illness for which only the most current data is useful.
- Often there will be a lag time, especially with big studies such as the Census. Most comprehensive surveys will be a few years old by the time they are published.
- Remember too that even if it is “old,” it may be the best we have right now because it has not been revisited recently. Admit the limitations of this kind of data and try to supplement it with other closely related research.

### Concluding Points:

- You are bringing your own credibility to the data, so it is important to set standards for yourself with regard to the data you plan to use. Researchers judge their data and the studies of others using the above criteria. You can use these criteria as well to assess the quality of data that you collected, assess the quality of other sources of data, and critique the data of your opponents.
- No data is perfect. Use your own judgment regarding the use of data you think is defensible. Knowing the assumptions behind the data you use will hold you to a good standard build your credibility for being a good source of information.

### **Commander DATA's Data Game:**

Commander DATA is a mock game show that's a fun way to learn the vocabulary of data and how to apply criteria to evaluate the merits of data. The exercise will help you build skills to identify gaps in data sources and determine the appropriate uses and limitations of health data when applying it to your policy and advocacy work. The Commander DATA game is in Appendix A.



## C. Determining the Data You Need

### Learning Objectives:

- Identify relevant and appropriate data needed for community stakeholders and policymakers
- Identify research questions that can be answered with data

Data can play a critical role in explaining why an issue is important. Whether you are talking to policymakers such as legislators or boards of directors, community stakeholders, or the media, data can persuade, convince and motivate action. Before beginning a search for data, it is important for you to outline and define the questions you need the data to answer.

To determine the data you need, answer these questions:

- ✓ What do I need the data to do?
- ✓ What message does the data have to deliver?
- ✓ Who are the audiences for the data, and what data does each audience need?

### **What do you need the data to do?**

- Define the problem
- Show that your solution alleviates or solves the problem
- Show the negative consequences of not using your solution
- Measure program outcomes

At any given time, you may need the data to do all these things, some of these things, or just one. To determine what you need the data to do, get a picture of your social, economic, and political environment:

1. What are the key public health issues for your community?
2. Define the problem central to the issue: i.e. access to health care, insurance, public attitudes and practices, etc. Think about how these affect your community.
3. Who are the stakeholders in these issues? Stakeholders are those individuals or organizations who have a “stake” in the issue. Some examples may include: Taxpayers, community activists, community-based organizations, businesses, health departments, justice departments, survivors, researchers, etc. What makes them stakeholders and what do they have to gain from supporting or opposing health policies?
4. What are the policies that would impact these issues? For example, a policy could be a code of ethics by advertisers to eliminate tobacco advertising to children, stronger penalties for selling tobacco to minors, supporting mammography detection programs, etc.

5. Who has the power to advance the policies you have identified? Consider in particular policymakers at the local level in your community such as: health departments, service providers, financial institutions, law enforcement, elected officials, insurance companies, professional organizations, trade associations, etc.
6. Barriers/Facilitators: What are the challenges to enacting your policy? Who are your allies? Who are your opposition?

Now that you have “mapped out” your issue, you can now begin to determine the data you need to:

- State the problem accurately in a compelling way;
- Show how your solution would alleviate the problem;
- Illustrate the negative consequences of not doing it;
- Refute arguments the opposition will use against you.

### **What message will the data deliver?**

- Cost?
- Quality?
- Access?
- Equity?
- Rights?

What is the message that the data will deliver? What will mobilize your stakeholders and motivate the decision makers into action? Different things will convince different people. For some, the statistics alone will motivate them; for others a more personal story of overcoming hardships will be the key.

In either case, the statistics and the stories are most effective when they appeal to someone’s values. If you can supply data that not only accurately describes what people experience and data that appeals to their values or belief system, then you have some very powerful tools with which to achieve your goals.

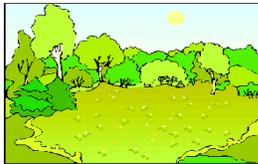
Some common values that data can address are cost, quality, access, equity, and rights.

- *Cost*—what is the cost of the problem to taxpayers, community, business, individuals, and others.
- *Quality*—how is quality of life, environment, services, and programs impacted?
- *Access*—who has access to services, programs, insurance, jobs, education, clean air, etc.? Who doesn’t?
- *Equity*—is there an equitable distribution of resources among segments of a community?
- *Rights*—what are the rights of members of a community? What laws, regulations, or constitutional protections confer rights and on whom are the rights conferred?

## What data does your audience need?

- Elected officials, juries, media, general public need data to understand the scope of the problem (the forest)
- Committee staffs, judges, special interest groups with legislative analysts need more specific information on who and what is impacted (individual trees)
- Agencies, courts, academics need details and statistics (roots)

The data you need not only depends on what you are trying to do, but also whom you have to convince. Some of this depends on the amount of time you have to present your position or the depth of information that you decide is appropriate. In general, the level of complexity you use when presenting data depends on the people you are trying to convince and their data needs.



**The Forest -- *Big Picture*:** Politicians, the general public and the media are audiences who tend to need information that is descriptive and easy to understand, often from an overall perspective or big picture point of view. The following is an example of “forest” type data from the Intercultural Cancer Council: American Indians and Alaska Natives have the poorest survival from “all cancers combined” as compared to any other racial/ethnic group (see *(see <http://iccnetwork.org>)*)



**Individual Trees -- *Some Details*:** Committee staff, judges, and special interest groups with legislative analysts tend to need more detail than the big picture. These individuals want to know what kind of trees are in the forest or how many trees per square acre. They may want to know if they clear this part of the forest, what does that do to the ecosystem, etc. This information will have more layers to it; often the audience understands the general ideas, but does not understand the details. An example of data that provides some details about an issue is this one: The five-year relative survival rate for American Indian women with breast cancer continues to be the poorest of any racial group in the U.S. (Burhansstipanov et al. 1999; Burhansstipanov and Hollow 2001; Kaur p.c. 2000).



**Roots -- *Specific Details*:** Government agencies, court officials, and academic institutions often need data to be more academically focused or statistically driven to understand and critique. This type of data may require a high degree of accuracy because funding or planning decisions will be made based on the numbers. These audiences need to have as much detail as possible. Here’s an example of “roots” data: The five-year survival rate for breast cancer among American Indians throughout the U.S. appears to be between 40% (Kaur p.c. 2000) and 48% (National Cancer Institute 1992). This situation may be due in part to the fact that Native women are often diagnosed with advanced staged tumors (Li et al. Differences in Breast Cancer Stage, Treatment, and Survival by Race and Ethnicity. *Arch Intern Med* 163:49-56, 2003).

**Determining the Data You Need Brainstorming Activity:**

Brainstorm about the data needed to address a community health issue. Create a list of community health issues of concern to your community. Identify one issue that is a priority. Next brainstorm about problems related to that issue that impact the community. Who has an interest in the issue and what data will they need to persuade them to be involved or counter their opposition? What policy solution is needed to address the issue and what data do you need to support your policy or program solution? Who are the policy makers who have the authority to adopt the policy and what data will they need?

Here's an example using the issue of childhood obesity. A blank worksheet to use in your brainstorm activity is in Appendix B.

Community Health Issue	Problem(s) associated with issue	Stakeholders (pro/con) in the Issue and data needed to persuade support, counter opposition	Policy/program Solutions And data that support solution	Policymakers with authority to adopt policy and data needs
Childhood obesity	<ul style="list-style-type: none"> <li>• Lack of food choices</li> <li>• Inability to exercise during school day</li> <li>• Lack of safe play environments afterschool</li> <li>• Heightened risk of diabetes, heart disease, cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Schools: data on impact of obesity on academic performance, attendance</li> <li>• Food service providers: data supporting cost effectiveness</li> <li>• Commercial establishments: data demonstrating consumer demand for healthy food choices; concern about obesity influencing food choices</li> </ul>	<ul style="list-style-type: none"> <li>• Enable better food choices: cost data on missed attendance v. revenue gain from non-healthy foods</li> <li>• Establish fitness programs: data showing association between fitness and academic performance</li> </ul>	<ul style="list-style-type: none"> <li>• Legislature, city councils, policy agencies, and school boards: local data on obesity impact, constituency (stakeholder) support for policy solution</li> <li>• Corporate voluntary policy: consumer support for healthy product choices</li> </ul>

You can begin your search for specific data by “cutting the data question.” That is, what specific data are needed? “Cutting the data question” provides you with basic research questions to focus your search for data.

## Cutting the Data Question

When looking for data, consider the following questions before you begin your search:

- ✓ What is the **Problem/Issue** you are trying to resolve?
- ✓ What is the **Cause** of the Problem?
- ✓ What are the **Effects** of the Problem?
- ✓ What are the characteristics of the **Population**?
- ✓ Does **Geography** have an effect on the problem?



## D. Finding Data

### Learning Objectives:

- Learn effective means for narrowing data searches and finding data
- Collect, summarize, and interpret information relevant to a specific public health problem
- “Localize” data and create local estimates using national and state level data
- How to combine quantitative and qualitative data

### Framing your argument

Your first step is to determine the health problem or issue you want to address. It is important to be as specific as possible about the issue or problem before starting your data search. Your health focus, population of interest and geographic area will help you conceptualize the different types of data that you will need and where you may go to access the data. Use the *Argument-Counter Argument Worksheet* to help you formulate your argument (see Appendix C).

### Data search challenges

There are three themes that may arise during your data search.

1. **Limited Resources:** Organizations may lack the internal capacity to search for appropriate data or fully utilize the data that they find. Often the organizations may not have the time, knowledge base, and/or people power to access the data.

Plan to spend time looking for data when you do a campaign. Be realistic about how much time this is going to take you and the manpower and expertise that you will need. Getting the data you need can take weeks, or months. You should plan accordingly.

2. **Access:** The limited quantity or non-existence of certain data can be very problematic. It may take some time to find the data you need or it may require that you create a local estimate based on national or state data you find. See section below on how to make estimates using national or state data.
3. **Quality:** It can be difficult to determine the reliability of information, especially if time constraints are involved in the process. Refer to the five criteria for evaluating data (credibility, specificity, generalizability, reliability and timeliness).

## What can you do if the data you need are not available?

Sometimes the data you need may be limited or unavailable for your specific population. In these cases, you can try to *localize data*, or take existing data and show how it applies to your population of interest. The following approaches can help you localize data:

- A. Using Proxy measures
- B. Extrapolating national or state data to make local area estimates
- C. Painting a picture
- D. Asking a researcher

### A. Using Proxy Measures:

"Proxy" measures are information that can substitute for the data you need because it is closely related to your issue. For example, you may need recent elder poverty data for your neighborhood. Since Medi-Cal is limited to low-income persons, you could take the number of elders receiving Medi-Cal as an indicator or proxy of the poverty level of elders in the neighborhood (this would be an undercount since not all low-income elders are on Medi-Cal).

Similarly, you could use the number of emergency room visits for falls among older persons as a proxy of risk for all falls by the elderly. These data do not give you a precise number or rate of your problem, but the data provide useful comparisons between communities, such as, "The elderly rate of poverty in our neighborhood may be much higher than the city average, as shown by our higher rate of elders on Medi-Cal."

A major advantage of this approach is its low cost. The data can be relatively easy and inexpensive to collect. However, there are some concerns with bias. Your estimates may be biased because they are not able to capture actual rates or precise numbers but it does offer some estimates for when data are not available.

### B. Extrapolating From Existing Data:

Extrapolating involves taking a national or state pattern of a problem and applying that pattern to your local area. Diabetes, for example, is a condition that needs ongoing medical care. We know that there are large differences by race and age in the rates of diabetes. To estimate the number of persons with diabetes in your community based on national trends (you could also take state or county data if you have access to it), you can take the following steps:

1. Identify the diabetes rate (percent with diabetes) using the national data source. Obtain the rate for subgroups where there is variation (e.g. race, sex, age, income) For example, the diabetes rate for Latinos nationally is .02 for age 18-44, .143 for age 45-64, and .204 for age 65 and over.  
[Source: National Health Interview Survey, Table 8 at [http://www.cdc.gov/nchs/fastats/pdf/sr10\\_209.pdf](http://www.cdc.gov/nchs/fastats/pdf/sr10_209.pdf)]

2. Identify the number in the population for the same subgroups locally. For example, say your community has the following:
  - a. 30,000 Latinos ages 18-44,
  - b. 11,000 Latinos ages 45-64, and
  - c. 2,000 Latinos ages 65 and over.
3. Multiply the national rates by the local numbers and add them up.

Number of Latinos with diabetes in your community=

National Rates x Population in your community (by the different ages)

$$.02 \quad x \quad 30,000 \text{ (ages 18-44)} = 600$$

$$.143 \quad x \quad 11,000 \text{ (ages 45-65)} = 1,573$$

$$.203 \quad x \quad 2,000 \text{ (ages 65 and over)} = 410$$

Next add up the various populations with diabetes:

$$600 + 1,573 + 410 = 2,583$$

There are an *estimated* 2,500 Latinos with diabetes in your community.

Remember that this method does not provide “precise” data on your topic, but it offers a way to generate useful estimates that can be used in your program planning and policy advocacy work.

### C. Paint a Picture

If you are unable to find the exact numbers you need to describe the impact of a health issue in your community. You can PAINT A PICTURE with the information you do have. The approach allows you to piece together data from several sources to illustrate your argument. It also allows you to use anecdotal information that can compliment your statistical data. The *Paint a Picture Worksheet* at the end of this section guides you through the various steps (see Appendix C).

### D. Ask a Researcher

- If you find a particularly helpful study, it might be possible to contact the researcher to find out more.
- Expect that it will take time, many researchers have moved on to their next discovery by the time data from their last experiment becomes available to the public.
- When you do get data this way, pay attention to any caveats the researcher places on the data, these caveats may be the reason the researcher did not publish that information, even if he/she found it interesting.
- Seek out those sources of information that provide ongoing support or technical assistance.

**Important Notes:**

- ❑ Obtain data from a CREDIBLE source that resembles/approximates the data you need.
- ❑ Consider the TIMELINESS and GENERALIZABILITY of the data. Note the similarities and differences between the demographics of the data and the demographics of your constituents.
- ❑ What will the estimate be used for? Is it appropriate to estimate in certain instances?
- ❑ Sometimes no number is better than a bad one; sometimes a fuzzy one is better than none. You must decide.
- ❑ Be prepared to defend the information you use and your methods for getting it.

**Combining Quantitative and Qualitative Data**

Keep in mind that there are two different kinds of data you may encounter through your data search, quantitative and qualitative.

*Quantitative data* are usually measured and expressed in the form of numbers or percentages. This data answers who, what, when and where.

*Qualitative data* are usually measured and expressed in the form of words, concepts, themes, or categories rather than numbers. Qualitative data is often used to gain a more in-depth understanding of a particular incident or phenomenon—answering how or why something is occurring.

The following are some important distinctions between quantitative and qualitative data:

	Quantitative	Qualitative
<b>DESCRIPTION</b>	<ul style="list-style-type: none"> <li>• Measured and expressed in the form of numbers or statistics</li> <li>• Also called numeric data</li> <li>• Can answer the who, what, when and where of an issue</li> </ul>	<ul style="list-style-type: none"> <li>• Measured and expressed in the form of words, stories or themes</li> <li>• Also called anecdotal data</li> <li>• Can answer the how or why</li> <li>• Used to gain a more in-depth understanding of an issue</li> </ul>
<b>DATA COLLECTION METHODS</b>	<ul style="list-style-type: none"> <li>• Secondary data</li> <li>• Surveys</li> <li>• Interviews</li> </ul>	<ul style="list-style-type: none"> <li>• Observations</li> <li>• Focus group</li> <li>• Surveys</li> <li>• Interviews</li> </ul>
<b>BENEFITS</b>	<ul style="list-style-type: none"> <li>• Can demonstrate cause and effect</li> <li>• Can “represent” a community by capturing the perspectives of many respondents</li> <li>• Usually easier to interpret</li> </ul>	<ul style="list-style-type: none"> <li>• Richer, more in-depth information about the topic being studied</li> <li>• Can provide data from a respondent in their own words</li> <li>• Can collect new data and new ideas from respondents in a dynamic and unstructured way</li> </ul>
<b>DRAWBACKS</b>	<ul style="list-style-type: none"> <li>• Unable to provide rich, in-depth data</li> <li>• Cannot collect new ideas or responses – you are restricted to the data that has already been collected</li> </ul>	<ul style="list-style-type: none"> <li>• Cannot demonstrate cause and effect</li> <li>• Usually not able to “represent” a community</li> <li>• Can be difficult to interpret</li> </ul>

Note that surveys and interviews can collect quantitative or qualitative data, depending on whether the question is asked in a closed- or open-ended format.

- An example of a closed-ended question may be: How many times have you seen a doctor during the past six months? Answer choices: 0, 1-2, 3-4, 5 or more.
- An example of an open-ended question may be: What challenges, if any, have you faced when trying to see a doctor in the past six months?

If possible, it is recommended that both kinds of data be collected and used in drafting your policy or program proposal because they serve two very different and necessary functions when attempting to paint a complete picture of your health problem or issue. Quantitative data can describe the size of a health problem and determine its associations with other issues, such as demographic factors or insurance coverage. Qualitative data can help give meaning and appropriate interpretation of the quantitative data, as well as answering “why” and “how”.



## E. Presenting Data

Using tables or graphs provides a useful visual presentation of the data.

### Tables:

- Suitable for providing simple or more complicated numeric or percentage information
- Best used for side-by-side comparison of data for various variables or groups
- Important to use when you want to show the exact numeric or percentage values
- Here is an example of a table that was used to show results in a research report about diabetes from the California Health Interview Survey (AL Diamant, SH Babey, ER Brown, N Chawla. *Diabetes in California: Findings from the 2001 California Health Interview Survey*. Los Angeles: UCLA Center for Health Policy Research, 2003.) The full report is available at:

<http://www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=68>

EXHIBIT 13. PERCENT WITH EACH TYPE OF USUAL SOURCE OF CARE BY TYPE OF INSURANCE, ELDERLY ADULTS WITH DIABETES, AGES 65 AND OVER, CALIFORNIA, 2001				
USUAL SOURCE OF CARE	MEDICARE AND MEDITAL	MEDICARE AND OTHER	MEDICARE ONLY	OTHER ONLY
DOCTOR'S OFFICE/KAISER/HMO	80.7	94.8	76.7	80.4
GOVERNMENT/COMMUNITY CLINIC	6.6	1.4	*	*
OTHER CLINIC/HOSPITAL CLINIC	8.9	3.0	*	*

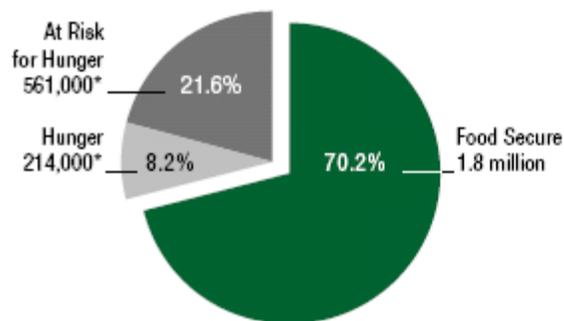
Note: The number of uninsured elderly adults was too small to present estimates for type of usual source of care. The number of elderly adults with no usual source of care or who used the emergency room as a usual source of care was too small to present estimates. Elderly adults who reported some other type of usual source of care were not included in the table because of their small sample size.

\* The estimate was not statistically reliable.

Source: 2001 California Health Interview Survey

### Pie Charts:

- Best when you have simple percentages and the “slices” of the pie are not too numerous
- Ideal for depicting the size of each part as a percentage of the whole
- Avoid dividing the pie graph into too many “slices”. It can lead to confusion when interpreting it
- Important to make sure the grayscale or patterns you use to represent the different “slices” are clear and distinguishable from one another. The best option is to display in color, if possible.
- Here is an example of a pie chart that was used to show results from a research report on hunger in Los Angeles County from the California Health Interview Survey (DiSogra CA, Yen W, Flood M, and Ramirez A. *Hunger In Los Angeles County Affects Over 200,000 Low-Income Adults, Another 560,000 At Risk*. Los Angeles: UCLA Center for Health Policy Research, 2003.) The full report is available at: <http://www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=92>



\*A total of 775,000 food-insecure adults

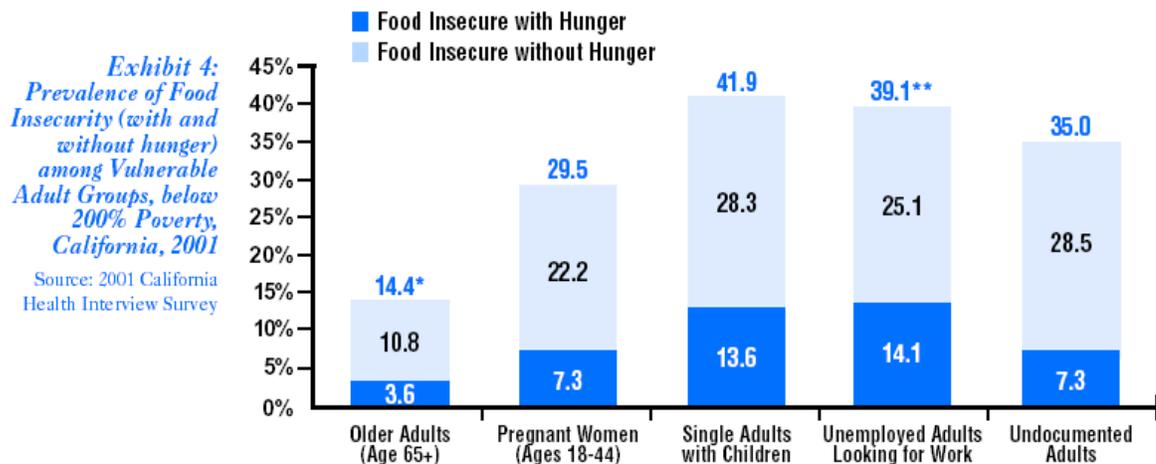
**Exhibit 1:**  
*Food Insecurity among  
 2.6 Million Adults with  
 Family Incomes Less  
 Than 200% FPL,  
 Los Angeles County*  
 Source: 2001 California  
 Health Interview Survey

## Bar Graphs:

- Good for comparing quantities – simple bar lines are easy to read and compare
- Avoid comparing things that are on different scales—uneven scales can lead to confusion when interpreting the graph
- Important to make sure the grayscale or patterns you use to represent the different "bars" are clear and distinguishable from each other. The best option is to display in color, if possible.
- Here is an example of a bar graph used to show results in a research report about food insecurity in California from the California Health Interview Survey (GL Harrison, CA DiSogra, G Manolo-LeClair, J Aguayo, and W Yen. *Over 2.2 Million Low-Income California Adults Are Food Insecure; 658,000 Suffer Hunger*. Los Angeles: UCLA Center for Health Policy Research, 2003.) The complete policy brief is available at:  
<http://www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=58>

### Example 1:

Over 2.2 Million Low-Income California Adults Are Food Insecure; 658,000 Suffer Hunger

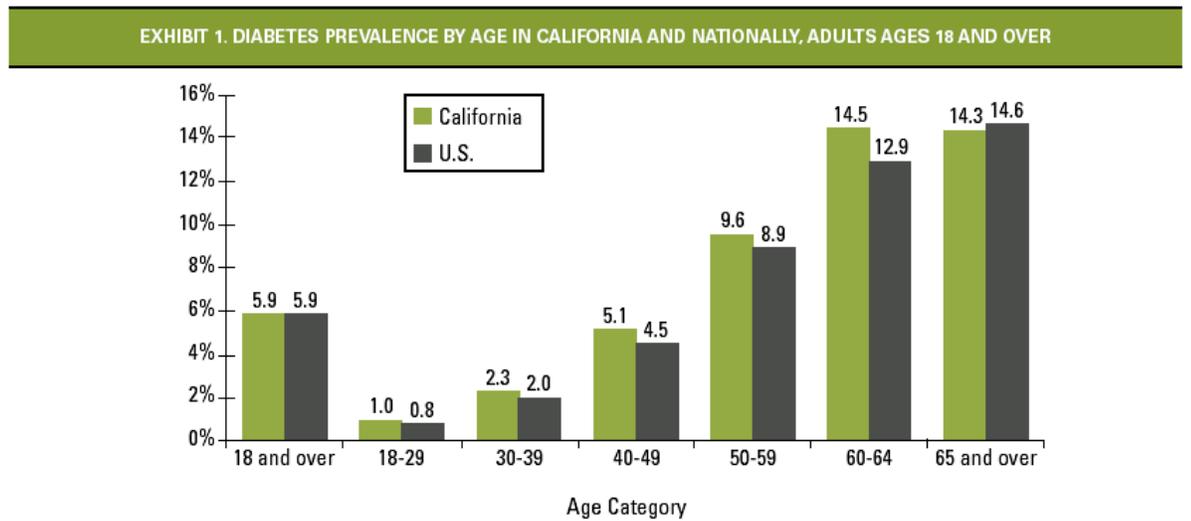


\*Top numbers represent total prevalence of food insecurity (with or without hunger) for each group.

\*\*Total prevalence of food insecurity does not add up due to rounding.

- Here is another example of a table that was used to show results in a research report about diabetes from the California Health Interview Survey (AL Diamant, SH Babey, ER Brown, N Chawla. *Diabetes in California: Findings from the 2001 California Health Interview Survey*. Los Angeles: UCLA Center for Health Policy Research, 2003.) The full report is available at: <http://www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=68>

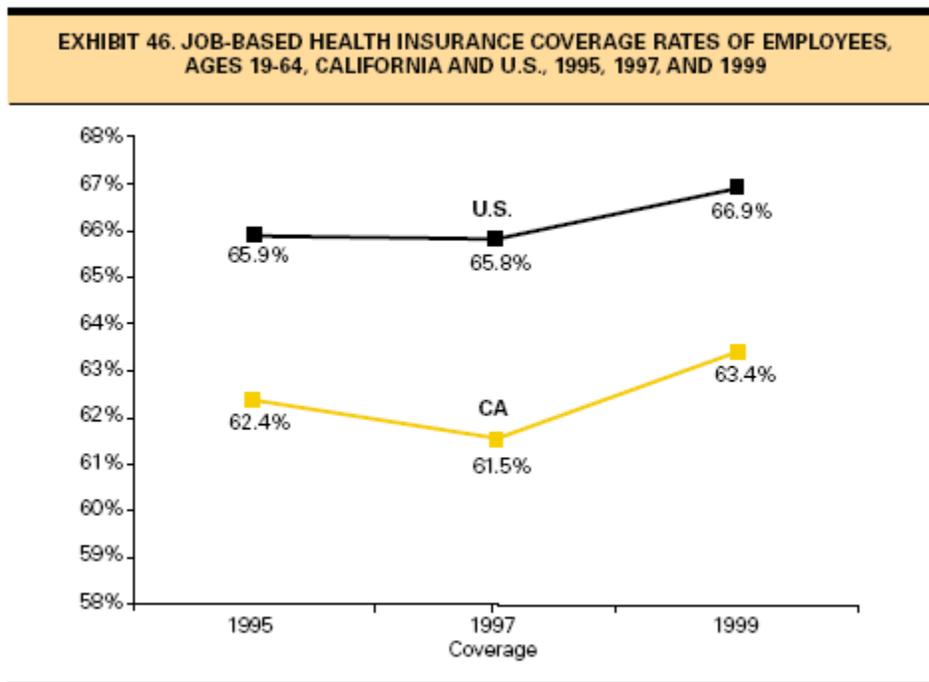
### Example 2:



Source: 2001 California Health Interview Survey and 2000 National Health Interview Survey

### Line Graphs:

- Excellent choice when illustrating trends over time
- Line movement, up and down, is easy to understand and interpret
- Here is an example of a line graph that was used to show results from a research report on health insurance from the California Health Interview Survey (ER Brown, N Ponce, T Rice, SA Lavarreda. *The State of Health Insurance in California: Long-Term and Intermittent Lack of Health Insurance Coverage*. Los Angeles, CA: UCLA Center for Health Policy Research, 2003.) The full report can be found at: <http://www.healthpolicy.ucla.edu/pubs/publication.asp?pubID=78>



Source: February 1995, 1997, and 1999 Current Population Surveys



## **Appendices**

Appendix A: Commander DATA's Data Game Q & A  
Health Data Toolkit

Appendix B: Data Needs Worksheet

Appendix C: Argument-Counter Argument Worksheet

Appendix D: Painting A Picture Worksheet

Appendix E: Data Resources



**APPENDIX A:       COMMANDER DATA'S DATA GAME Q & A  
HEALTH DATA TOOLKIT**



## Commander DATA's Data Game Examples Apply Criteria for Evaluating Data to these Examples

According to the Community Research Initiative on AIDS, 21 of 1,000 male prisoners and 35 of 1,000 female prisoners were known to be HIV positive at the end of 1997. The **rate** of confirmed AIDS was 5½ times higher in the prisons than in the general population. A study of infectious diseases among people passing through correctional facilities in 1996 found that 17% of those released from prison were HIV positive. Available at: <http://www.thebody.com/cria/summer00/prison.html>

In October 1997 the Office of Management and Budget (OMB) issued revised federal standards for collecting and presenting data on race and ethnicity. As a result, changes were made to the **methodology** of the 2000 Census, to allow respondents to “check all that apply” when indicating their ethnicity.

A tobacco company released the results of a survey conducted on a **sample** of 1000 smokers' families and found second hand smoke is not a “noticeable health risk.”

According to scientists at the Greening Earth Society, many scientists **estimate** that human industrial activity will increase global CO<sup>2</sup> levels to 750 ppm and beyond. Our use of fossil fuels is helping give plants the extra CO<sup>2</sup> they need to grow more lush and green worldwide. Available at: <http://www.greeningearthsociety.org/Articles/2001/bad.htm>

A community based organization working to increase Healthy Families and Medi-Cal enrollment has just released **quantitative** data from a survey they conducted in one zip code with 500 households. The data shows that the problem of uninsured children in this zip code is twice that of Los Angeles County as a whole.

In 2000, the Drug Abuse Warning Network publicized results of their annual report of Emergency Department visits. Through a **qualitative** study, involving visual identification of “drug abuse episodes,” among a sample of people 6 to 97 years of age, it was estimated that 243 out of every 100,000 visits to the emergency room were related to drug abuse. Available at: <http://www.samhsa.gov/oas/majorDAWN.pdf>

In an example of **anecdotal** data, a mother testified before the state assembly about the financial toll of raising her son with chronic asthma. Without insurance, her family was faced with a heavy financial burden whenever her son required medical care. The family cannot afford to pay for the inhaler and medication that the son needs, he is in and out of the emergency room, and has not been diagnosed with a learning disability.

In a report titled, Disparities in Health Insurance and Access to Care for Moderate- and Low-Income Residents Across American Cities, the Center for Health Policy Research noted that 31.5% of the residents of Los Angeles between the ages of 0 and 64 are uninsured compared to the average value across 85 metropolitan areas of 17.1%. Age was one **variable** of several used in the report to compare insurance coverage among populations in California. Available at: <http://www.healthpolicy.ucla.edu/data.html>



## Health DATA Toolkit

### TYPES OF DATA

**Qualitative:** Data that is usually measured and expressed in the form of words, concepts, themes, or categories rather than numbers. Qualitative data are often used to gain a more in-depth understanding of a particular incident or phenomenon – they answer how or why something is occurring.

Qualitative techniques include, but are not limited to:

- Observation
- **Ethnography:** the study and subsequent recording of information about human culture
- **Case study:** a study based on an intensive observation of one (or a few) cases or examples, such as organizations or events.
- Open-ended interview\*
- **Focus group:** a group of individuals led through a structured discussion of a particular topic or event. Focus groups are often used to assess social needs, develop hypothesis and survey questions, investigate the meaning of survey results, and assess the range of opinions.

**Quantitative:** Data that is usually measured and expressed in the form of numbers or statistics and which usually answer the who, what, when and where questions of a research problem.

Quantitative techniques include, but are not limited to:

- **Census:** a complete enumeration of the population
- **Survey\*:** A systematic way of collecting information from a defined population, usually by means of interviews or questionnaires administered to a sample of the population.
- **Questionnaire\*:** a method of collecting data by asking participants identical questions about a particular issue or issues. Questions may be open-ended (the answer is completely left up to the respondent) or close-ended (where respondents are presented with a limited number of options to reply, such as yes/no, true/false or Likert-scale responses.
- Close ended interview\*

\* NOTE: Interviews, Questionnaires and Surveys can be quantitative, if utilizing a close-ended format, or they can be qualitative, if a more open ended format is used.

## METHODOLOGY – “HOW DID YOU GET THE DATA?”

**Anecdote (-al):** A particular incident or fact of note used to illustrate a situation. Often, a descriptive story or information gained from day-to-day experiences, but not systematically.

**Bias:** Any factor that prevents research from providing a representative sample for the population being studied.

**Cross-section:** a cross-sectional research design is one in which all data are collected at one point in time. The purpose is to easily identify whether there is an association between two variables.

**Estimate:** A number drawn from a sample that is intended to describe the population from which the sample is drawn.

**Likert-scale:** A research design that utilizes scaled responses such as strongly agree, agree, neutral, disagree, and strongly disagree to elicit participant feelings about a research topic.

**Longitudinal:** a study in which data from the same population are gathered at two or more distinct points in time. This allows the researcher to identify trends and changes over time and more closely determine if there is a cause and effect association between two variables.

**Methodology:** A structured approach used to answer specific questions or test the hypothesis in a study. Can be called the “science of finding out.”

**Population:** Entire group of individuals, who are logically related in some way, about which information is desired.

**Random:** A method of research that assigns every member of a group the same chance of being chosen to be a respondent. (Note: Choosing every 10<sup>th</sup> person from an alphabetized list is not random since some ethnicities will have names that cluster in a few letters, while others will be spread throughout; in contrast, picking names out of a hat is random)

**Random Assignment or randomization:** Assignment of research subjects by chance into a study or survey. Randomization helps to eliminate potential bias.

**Response rate:** the proportion of subjects who were asked to participate in the study that completed the survey. Poor response rates may indicate some bias because those who chose to respond may be different in important ways from those who did not respond.

**Sample:** The subset of a population selected for study. Because it is often costly to interview a whole population (for example, the entire population of California), a sample of Californians are interviewed, who represent the whole population. They are usually selected based on the criteria (variables) essentially to answering the research question.

**Triangulation:** Determining the applicability of data gathered from a variety of sources, using differing research methods, to answer a particular research question.

**Variable:** any characteristic of a research participant that can be expressed as a number. Variables are often in the form of attributes such as sex, age, employment status, income, etc...

### **DATA INTERPRETATION – “WHAT DO THE NUMBERS MEAN?”**

**Average:** the value that is intended to represent the general value, central tendency, of a set of unlike numbers. It is computed by adding the values of all the cases and dividing by the total number of cases.

**Cause (-ation):** the reason something happens.

**Correlation:** two events that change in concert with each other. A correlation does not mean cause and effect. For example, early in the AIDS epidemic it was noticed that the more often people used “poppers” (the stimulant amyl nitrate) the more likely they were to get AIDS. While these two were “correlated,” it turned out that poppers were not the cause of AIDS, but were most commonly used by gay men during sex.

**Incidence:** the number of NEW cases during a period of time (e.g. the number of people newly diagnosed with HIV in the year); this number is useful to tell you about changes in the number of people affected by the condition.

**Indicator:** a measure that is closely associated with or a component of a condition you are studying. For example, mortality is a “health indicator” -- higher death rates are taken to mean that a population is less healthy even though death is a very crude way to measure “health.”

**Mean:** see average

**Median:** **the value in a distribution of numbers that falls directly in the middle, such that 50% of the values lie below and 50% of the values lie above that value.**

**Mode:** the most frequent value in a distribution. Also termed probability average.

**Percentage:** A proportion where the denominator is expressed as 100;  $\frac{1}{4}$  is 25/100, expressed as 25%. (See proportion)

**Prevalence:** the number of EXISTING cases at a point in time (e.g. the number of people living with HIV at this moment).

**Proportion:** the number of persons (or events) of interest divided by the total number of persons in the population (or events). If 100 persons have a disability in a community of 400, then  $\frac{1}{4}$  are disabled.

**Range:** the true upper limit in a distribution minus the true lower limit. It is measure of variability.

**Rate:** Indicates the frequency of a given event (e.g., 100 births per 1,000 adults). It is a way of knowing the proportion of a population, possessing a particular variable, in order to compare areas or groups of different sizes.

**Standardized rate:** Populations often differ in characteristics related to the health issue under consideration, such as birth rates that vary with age. A younger population will have a higher birth rate than an older population. Standardizing portrays rates "as if" the characteristics of the two populations were the same (for birth and death rates it is often called age adjusted rates).

**Statistical significance:** The characteristic of an association that is not likely to be due to chance. In statistical terms, data are statistically significant if they meet certain criteria, often that the probability of error ( $p$ ) is less than 5 out of 100 ( $p < .05$ ).

**APPENDIX B:  
DATA NEEDS BRAINSTORMING WORKSHEET**



**Determining the Data You Need Brainstorming Activity:**

Brainstorm about the data needed to address a community health issue. Create a list of community health issues of concern to your community. Identify one issue that is a priority. Next brainstorm about problems related to that issue that impact the community. Who has an interest in the issue and what data will they need to persuade them to be involved or counter their opposition? What policy solution is needed to address the issue and what data do you need to support your policy or program solution? Who are the policy makers who have the authority to adopt the policy and what data will they need?

Community Health Issue	Problem(s) associated with issue	Stakeholders (pro/con) in the Issue and data needed to persuade support, counter opposition	Policy/program Solutions And data that support solution	Policymakers with authority to adopt policy and data needs



**APPENDIX C:  
ARGUMENT-COUNTER ARGUMENT WORKSHEET**



## Argument - Counter Argument Worksheet

In presenting a policy proposal, you need to formulate your own argument, anticipate opposing arguments and counter those arguments using data. The following chart is provided to help you organize your thoughts and data needs.

<ul style="list-style-type: none"><li>• <b>What is your message?</b></li><li>• What data will help you support your argument?</li></ul>	<ul style="list-style-type: none"><li>• <b>What arguments should you expect from your critics?</b></li><li>• What data might you expect them to provide?</li></ul>	<ul style="list-style-type: none"><li>• <b>What is your response?</b></li><li>• What data will you need to support your response to opponents?</li></ul>
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**APPENDIX D:  
PAINTING A PICTURE WORKSHEET**





# Health DATA "Painting A Picture" Worksheet

Are you unable to find the exact numbers you need to describe the impact of a health issue in your community? You can PAINT A PICTURE with the information you do have. The following steps will assist you to do this work. GOOD LUCK!



## DRAW YOUR PICTURE

### STEP 1: Define your argument.

#### What is your argument?

Clearly state what you are trying to do. Do you want to show that a problem exists or do you want to focus on strategies for improvement?

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#### Example:

We want the county to provide no-cost or low-cost patient educational and health care services that are culturally and linguistically appropriate to Latino children with asthma. Asthma is a serious health issue in Fresno County, especially among Latino children. Because many in the Latino community lack access to health care, it is difficult to manage this serious condition within the community.

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### STEP 2: Define your data needs.

#### What do you know about your community and issue that specifically pertain to the argument? Is this information documented and readily accessible?

Often, we already know what is going on in our communities from personal experience or pre-existing data. What data do you have that supports what you know? State that information.

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#### Is there information that you do not have about your community or issue, but need to help you make your argument?

What data would you ideally need to support your argument or make it stronger?

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#### Example:

- I know that Fresno County has the third highest asthma mortality rate in the United States. I also know that asthma is the leading cause of school

Continued on next page.

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**STEP 7: Organize the data you have to make a convincing argument.**

**What information will fit together to paint a picture that leaves no doubt about the importance of your argument?**



**Example:**

In Fresno, we have the third highest rate of people dying from asthma in the United States, and asthma is the number one reason for emergency room visits. According to the American Lung Association's *State of the Air 2000* report, there are 15,455 children with asthma in Fresno County. This problem is especially important in Fresno's Latino community. Latinos make up 42% of our population, and nearly four out of every ten Latinos in California do not have health insurance. For Latino children in this state, the risk of being hospitalized because of asthma is 65% greater than that for white children. If we invest money in asthma patient education and target these services to our Latino communities, we can save our county health care system money by reducing costs for emergency room visits.

Horizontal lines for writing notes or answers.

<sup>i</sup> American Lung Association of Central California, Fact Sheet. [www.amerilungcencal.org](http://www.amerilungcencal.org).  
<sup>ii</sup> California Department of Health Services.  
<sup>iii</sup> American Lung Association, *State of the Air 2000*. [www.lunqusa.org](http://www.lunqusa.org).  
<sup>iv</sup> National Asthma Education and Prevention Program of the National Institutes of Health.  
<sup>v</sup> California State Department of Finance, UCLA Center for Health Policy Research.

*Funded by The California Endowment, the Health DATA Program is a public service program of the UCLA Center for Health Policy Research. Health DATA works with community organizations to improve their capacity to find, understand, and present credible data in their health policy work.*

*The Health DATA Program would like to give a special thanks to Okeoma Mmeje, Raquel Donoso, and Martha Widmann for their invaluable contributions to this worksheet.*

**To contact the Health DATA Program:** UCLA Center for Health Policy Research  
10911 Weyburn Avenue, Suite 300  
Los Angeles, California 90024  
Phone: (310) 794-0658  
Fax: (310) 794-2686  
Web: [www.healthdata.ucla.edu](http://www.healthdata.ucla.edu)

## **APPENDIX E: DATA RESOURCES**



## Data Resources

### **State Information**

- State of California Home Page  
[www.ca.gov](http://www.ca.gov)
- California Senate  
[www.sen.ca.gov](http://www.sen.ca.gov)
- California Assembly  
[www.assembly.ca.gov](http://www.assembly.ca.gov)
- Legislative Analyst  
[www.lao.ca.gov](http://www.lao.ca.gov)
- Office of Administrative Law  
[www.oal.ca.gov](http://www.oal.ca.gov)
- Department of Social Services  
[www.dss.cahwnet.gov](http://www.dss.cahwnet.gov)
- Healthy Families program information  
[www.mrmib.ca.gov](http://www.mrmib.ca.gov)
- Partnerships Against Violence  
[www.pavnet.org](http://www.pavnet.org)
- The Violence Policy Center  
[www.vpc.org](http://www.vpc.org)

### **Health Departments**

- State of California, Health and Human Services Agency  
<http://www.oshpd.cahwnet.gov/hid/infores/DbInventory/inventory.htm>
- Los Angeles County Department of Health Services  
<http://lapublichealth.org>  
Office of Health Assessment and Epidemiology  
<http://lapublichealth.org/ha.index.htm>  
  
Los Angeles County Health Survey  
<http://lapublichealth.org/ha/haprog.htm>
- Riverside county Community Health Agency  
<http://www.rivcocha.org/>  
Department of Public Health  
<http://www.rivcohp.org/>  
  
Department of Environmental Health  
<http://www.rivcoeh.org/>

- County of San Bernardino Department of Public Health  
<http://www.co.san-berardino.ca.us/pubhlth/>
- Health Care Foundation of Orange County  
<http://www.hfoc.org/>

## **Health Statistics**

- United Way of Los Angeles  
[www.unitedwayla.org](http://www.unitedwayla.org)
- National Health Foundation  
[www.nationalhealthfdt.org](http://www.nationalhealthfdt.org)
- American FactFinder  
<http://factfinder.census.gov>
- Centers for Disease Control and Prevention  
Behavioral Risk Factor Surveillance System – Prevalence Data  
<http://www.cdc.gov/nccdphp/brfss/index.htm>
- National Center for Health Statistics  
<http://www.cdc.gov/nchs>
- Wonder Data Query System  
<http://wonder.cdc.gov/>
- National Library of Medicine\*\*  
<http://www.nlm.nih.gov/>
- The Combined Health Information Database\*\*  
<http://chid.nih.gov/index.html>
- National Center for Health Statistics\*\*  
<http://www.cdc.gov/nchs/index.htm>
- Dartmouth University  
Atlas of Health Care in the United States  
<http://www.dartmouth.edu/~atlas/>
- The Henry J. Kaiser Family Foundation  
<http://www.kff.org/>
- Mansfield University  
Statistical Resources – Section Health Statistics  
<http://www.mnsfld.edu/depts/lib/hstats.html>
- United States Census Bureau  
<http://www.census.gov/>
- United States Department of Health and Human Services  
Healthy People 2010  
<http://www.health.gov/healthypeople/>

- National Institutes of Health  
<http://www.nih.gov/>
- The Office of Minority Health and Resource Center  
<http://www.omhrc.gov/>
- Office of Women's Health - National Women's Health Information Center (NWHIC)  
<http://www.4women.org/>
- United States Department of Labor  
Occupational Safety and Health Administration (OSHA)  
<http://www.osha.gov/>
  - University of North Carolina  
Minority Health Database Catalog  
<http://www.minority.unc.edu/databases/mhd/>
  - University of California – Los Angeles  
Center for Health Policy Research  
<http://www.healthpolicy.ucla.edu/>

## **Health Policy Analysis**

- Health Policy Links  
<http://movingideas.org/links/healthlinks.html>
- The Health Reformer (free health literature)\*\*  
<http://www.healthreformer.org/freelit.php>
- Community Health Council Inc.\*\*  
<http://www.chc-inc.org/chcInside.cfm>
- learn more about national health and welfare policy issues that affect *Native Americans* and gain a better understanding of the national policymaking process\*\*  
<http://www.kff.org/docs/topics/nafellow.html>
- The Los Angeles County Wellness Council\*\*  
<http://www.lacwc.org/>
- Agency for Health Care and Policy Research  
<http://www.ahcpr.gov/>
- Attorney General  
<http://caag.state.ca.us/>
- Budget Bureau  
<http://www.nasbo.org/>
- Center for Public Integrity  
<http://www.publicintegrity.org/>
- The Commonwealth Fund  
<http://www.cmwf.org/>

- Department of Insurance  
<http://www.naic.org/>
- Economic Policy Institute  
<http://www.epinet.org/>
- Families USA Foundation  
<http://www.familiesusa.org/>
- The Health on the Net Foundation  
<http://www.hon.ch/>
- IntelliHealth  
<http://www.intelihealth.com/>
- The Mayo Clinic's Health Oasis  
<http://www.mayohealth.org/>
- National Association of Counties  
<http://www.naco.org/naco/index.cfm>
- National Health Law Program  
<http://www.healthlaw.org/>
- Physician for Social Responsibility (PSR)  
<http://www.psr.org/>
- The Public Forum Institute  
<http://www.publicforuminstitute.com/>
- Health Privacy Project at Georgetown University  
[www.healthprivacy.org](http://www.healthprivacy.org)
- The Urban Institute  
<http://www.urban.org>

### **California Health And Policy Resources**

- Agency for Healthcare Research and Quality (AHRQ)\*\*  
<http://www.ahrq.gov/>
- California Consumer - Health Scope  
<http://www.healthscope.org/>
- The California Budget Project  
<http://www.cbp.org/>
- The California Health Interview Survey  
<http://www.chis.ucla.edu>
- California Department of Finance  
<http://www.dof.ca.gov/>

- California Department of Health Services  
Center for Health Statistics  
<http://www.dhs.cahwnet.gov/org/hisp/chs/chsindex.htm>
- California HealthCare Foundation  
<http://www.chcf.org/>
- California Department of Health Services  
<http://www.dhs.cahwnet.gov/>
- California Department of Social Services  
<http://www.dss.cahwnet.gov/>
- California Office of Statewide Health Planning and Development (OSHPD)  
<http://www.oshpd.cahwnet.gov/>
- The California Endowment  
<http://www.calendow.org/>
- The California Wellness Foundation  
<http://www.tcfw.org/>
- Center for Health Improvement  
Health Policy Coach  
<http://www.policymatters.org/>
- The Forum for State Health Policy Leadership  
<http://www.ncsl.org/programs/health/forum/index.htm>
- Health Care Financing Administration (HCFA)  
<http://www.hcfa.gov/>
- Health Policy Tracking Service  
<http://www.hpts.org/>
- Jewish Family Service of Los Angeles  
<http://www.jfsla.org/>
- Latino Coalition for a Healthy California  
<http://www.lchc.org/>
- Medi-Cal Policy Institute  
<http://www.medi-cal.org/index.cfm>
- National Academy for State Health Policy  
<http://www.nashp.org/>
- National Conference of State Legislatures (NCSL)  
<http://www.ncsl.org/>
- National Governor's Association (NGA)  
<http://www.nga.org/>
- State and Regional Issues  
<http://www.healthlaw.org/state.shtml>

- Stateline.org  
<http://www.stateline.org/>
- StateServ  
<http://www.stateserv.hpts.org/>
- University of California  
California Policy Research Center  
<http://www.ucop.edu/cprc>
- UCLA Center for Health Policy Research  
<http://www.healthpolicy.ucla.edu>
- The 100 Percent Campaign: Health Insurance for Every California Child  
<http://www.100percentcampaign.org/>

## **Resources on Aging**

- American Association of Retired People  
<http://www.aarp.org/>
- Stop Elder Abuse\*\*  
<http://www.elderlyabuse.com/>
- Association for Protection of the Elderly \*\*  
<http://www.aepe.org/>
- National Institute of Arthritis and Musculoskeletal and Skin Diseases\*\*  
<http://www.niams.nih.gov/>
- Hospice Patient Alliance\*\*  
<http://hospicepatients.org/>
- The American Parkinson Disease Association, INC.\*\*  
<http://apdaparkinson.com/>
- Alzheimer's Disease Education & Referral Center\*\*  
<http://www.alzheimers.org/>
- Administration on Aging\*\*  
<http://www.aoa.dhhs.gov/>
- Arthritis Foundation\*\*  
<http://www.arthritis.org/>
- National Senior Citizens Law Center  
<http://www.nslc.org/>
- The Gerontological Society of America\*\*  
<http://www.geron.org/>
- National Osteoporosis Foundation\*\*  
<http://www.nof.org/>

- National Association on HIV Over Fifty\*\*  
[http://www.hivoverfifty.org/nahof\\_resources.html](http://www.hivoverfifty.org/nahof_resources.html)
- The Western Law Center for Disability Rights\*\*  
<http://wldr.everybody.org/special-programs/outreach.mason>
- National Council on Aging  
<http://www.ncoa.org/>

## **Children Health and Policy Resources**

- American Academy of Pediatrics  
<http://www.aap.org/>
- Children's Hospital Los Angeles \*\*  
<http://www.childrenshospitala.org>
- Council for Children with Behavioral Disorders\*\*  
<http://www.ccbd.net/>
- The California Adolescent Health Collaborative (AHC)\*\*  
<http://www.californiateenhealth.org/index.html>
- St. John's Well Child Center\*\*  
<http://www.wellchild.org/>
- American Academy of Pediatrics' Committee on Public Education (COPEd)\*\*  
<http://www.aap.org/visit/cmte11.htm>
- The Alliance for Children's Rights\*\*  
<http://www.kids-alliance.org/resources.asp>
- The Children's Defense Fund  
<http://www.childrensdefense.org/>
- National Health Law Program  
Children's Health  
<http://www.healthlaw.org/children.shtml>
- Children Now  
<http://www.childrennow.org/>
- Child Welfare League of America  
<http://www.cwla.org/>
- Family Voices  
<http://www.familyvoices.org/>
- Institute for Child Health Policy  
<http://www.ichp.edu/>
- National Center for Youth Law  
<http://www.youthlaw.org/>

- The Alliance To End Childhood Lead Poisoning  
<http://www.aecpl.org/>
- National Maternal and Child Health Clearinghouse  
<http://www.nmchc.org/>
- HCFA 's Children's Health Insurance Program Website  
<http://www.hcfa.gov/init/children.htm>

## **Condition Specific Resources**

- U.S. Department of Health and Human Services (Every illness know to man in alphabetical order)\*\*  
<http://www.nih.gov/health/InformationIndex/HealthIndex/Pubincov.htm>  
Consumer Health Publications  
<http://www.nih.gov/health/consumer/conkey.htm>
- American Academy of Allergy, Asthma & Immunology  
<http://www.aaaai.org>
- Francis J. Curry National Tuberculosis Center (CNTC)\*\*  
<http://www.nationaltbcenter.edu/>
- National Oral Health Information Clearinghouse\*\*  
<http://www.nohic.nidcr.nih.gov/>
- American Heart Association\*\*  
<http://www.americanheart.org/presenter.jhtml?identifier=1200000>
- Center for School Mental Health Assistance\*\*  
<http://csmha.umaryland.edu/csmha2001/main.php3>
- Breast Cancer Info Center\*\*  
<http://www.feminist.org/other/bc/bchome.html>
- Breast Cancer Action\*\*  
<http://www.bcaction.org/>
- American Cancer Society\*\*  
<http://www.cancer.org/>
- Suicide Prevention Resources\*\*  
[http://www.guidancechannel.com/links\\_cat.asp?cat=8](http://www.guidancechannel.com/links_cat.asp?cat=8)
- United States National Institute of Diabetes & Digestive & Kidney Diseases\*\*  
<http://www.niddk.nih.gov/>
- Children and Adults With Attention-Deficit/Hyperactivity Disorder\*\*  
<http://www.chadd.org/index.htm>
- The National Alliance for the Mentally Ill (NAMI)\*\*  
<http://www.nami.org/history.htm>

- Autism Society of America\*\*  
<http://www.autism-society.org/>
- American Cancer Society  
<http://www.cancer.org>
- American Association of Obesity  
<http://www.obesity.org>
- Athealth.com-Depression  
<http://www.athealth.com>
- CancerNet  
<http://www.cancernet.gov>
- MyAsthma  
<http://www.myasthma.com>
- National Heart, Lung and Blood Institute  
<http://www.nhlbi.nih.gov>
- National Institute of Mental Health  
<http://www.nimh.nih.gov>
- Obesity Online  
<http://www.obesity-online.com>
- OncoLink  
<http://www.oncolink.com>

## **Environmental Health Resources**

- Earth's 911  
<http://www.1800cleanup.org>
- Enviroknowledge  
<http://www.enviroknowledge.com>
- Environmental Organization Web Directory  
<http://www.webdirectory.com>
- Thurgood Marshall School of Law  
Environmental Justice Clinic  
<http://www.tsulaw.edu/environ/environ.htm>
- Environmental Protection Agency-EPA  
Federal Register  
<http://www.epa.gov/fedrgstr/index.html>
- EPA Environmental Justice Homepage  
<http://www.epa.gov/docs/swerosps/ej/index.html>
- Environmental Working Group  
<http://www.ewg.org>

- Global Response  
<http://www.globalresponse.org>
- Healthy Schools  
<http://www.healthyschools.org/index.html>
- League of Conservation Voters  
<http://www.lcv.org>
- Right-to-Know Network  
<http://www.rtk.net>
- Children's Environmental Health Network  
<http://www.cehn.org/>
- Center for Health Environment and Justice  
<http://www.chej.org/>

## **Government Policy Resources**

- Federal Government Website  
<http://www.firstgov.gov/>
- The United States General Accounting Office (GAO)  
<http://www.gao.gov/>
- Government Printing Office  
<http://www.access.gpo.gov/>

## **Health Advocacy Resources**

- Alan Guttmacher Institute  
<http://www.agi-usa.org/>
- Health Advocacy Organizations by Name \*\*  
<http://www.healthfinder.gov/scripts/SearchContext.asp?topic=13&Branch=6&show=1>
- Patient Advocate Foundation\*\*  
<http://www.patientadvocate.org/>
- Joint Commission Accreditation Healthcare Organizations\*\*  
<http://www.jcaho.org/who+am+i.htm>
- The Health Resource Medical Information Service's\*\*  
<http://www.thehealthresource.com/index.html>
- The 100% Campaign\*\*  
<http://www.100percentcampaign.org/about.html>

- INMED\*\*  
<http://www.inmed.org/who.htm>
- The American Accreditation HealthCare Commission / URAC  
<http://www.urac.org/>
- Consumer Health/Agency for Health Care Policy and Research  
<http://www.ahcpr.gov/consumer>
- Consumer Resources  
<http://www.healthlaw.org/consumer.shtml>
- Consumers Union Health Care Index  
<http://www.consunion.org/health/health.htm>
- Cornell Legal Information Institute  
<http://www.law.cornell.edu/>
- Findlaw.com  
<http://www.findlaw.com/>
- Freedom of Information and Privacy at Health Care Financing Administration  
<http://www.hcfa.gov/foip>
- Foundation for Accountability (FACCT)  
<http://www.facct.org/>
- Health Consumer Alliance  
<http://www.healthconsumer.org/>
- Health Hippo  
<http://hippo.findlaw.com/>
- Health Insurance Information, Counseling and Assistance (HIICAP)  
<http://hiicap.state.ny.us/>
- The Health Law Resource  
<http://www.netreach.net/~wmanning>
- Healthfinder  
<http://www.healthfinder.gov/>
- Hieros Gamos  
<http://www.hg.org/index.html>
- The Internet Law Library  
<http://uscode.house.gov/>
- The Joint Commission on Accreditation HealthCare Organizations  
<http://www.jcaho.org/>
- Law Library Resource Exchange  
<http://www.llrx.com/>

- Med Help International  
<http://medhlp.netusa.net/>
- National Committee for Quality Assurance (NCQA)  
<http://www.ncqa.org/>
- Patient Advocacy Numbers  
<http://infonet.welch.jhu.edu/advocacy.html>
- President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry  
<http://www.hcqualitycommission.gov/>
- Public Accountability  
<http://www.healthlaw.org/pubaccount.shtml>
- The Virtual Chase  
<http://www.virtualchase.com/index.shtml>

## **Health Insurance Resources**

- The Health Consumer Center of Los Angeles\*\*  
<http://www.healthconsumer.org/LosAngeles.html>
- HARP is a resource for patients, doctors, and attorneys seeking to establish the liability of HMOs, Managed Health Care Organizations, and Nursing Facilities for the consequences of their decisions.\*\*  
<http://harp.org/>
- Californian Health Care Council\*\*  
<http://www.cchcc.org/>
- Managed Care  
<http://www.healthlaw.org/managedcare.shtml>
- Health Advocacy Resources by Counties\*\*  
<http://www.cwda.org/resources.cfm?SECT=6>
- The Henry J. Kaiser Family Foundation  
<http://www.kff.org/>
- Managed Care Central  
<http://www.familiesusa.org/>
- Health Care Financing Administration Managed Care Websites  
<http://www.hcfa.gov/medicare/mgdcar.htm>
- *HIICAP Managed Care/HMOs Page*  
<http://www.hiicap.state.ny.us/hmos/index.htm>

## **HIV/AIDS Resources**

- Critical Path AIDS Project  
<http://www.critpath.org/>
- A good AIDS and HIV resource list\*\*  
<http://www.thebody.com/index.shtml>
- National Institutes of Health  
Office of AIDS Research  
<http://www.nih.gov/od/oar>
- National Minority AIDS Council (NMAC)  
<http://www.nmac.org/>
- University of California – San Francisco  
Center for AIDS Prevention Studies (CAPS)  
<http://www.caps.ucsf.edu/>
- University of California – San Francisco  
HIV Insite  
<http://hivinsite.ucsf.edu/>

## **Immigrant Health Resources**

- Immigrant Health  
<http://www.healthlaw.org/immigrant.shtml>
- DiversityRX  
<http://www.diversityrx.org/>
- National Immigration Law Center\*\*  
<http://www.nilc.org/>
- The Working Immigrant Safety and Health Coalition\*\*  
[http://ist-socrates.berkeley.edu/~lohp/Projects/Immigrant\\_Workers/immigrant\\_workers.html](http://ist-socrates.berkeley.edu/~lohp/Projects/Immigrant_Workers/immigrant_workers.html)
- Massachusetts Immigrant Health Access Coalition  
<http://www.hcfama.org/>
- New York Task Force On Immigrant Health  
<http://www.med.nyu.edu/NYTFIH/>
- Immigrant Policy Project at the National Conference of State Legislature  
<http://www.ncsl.org/statefed/ipphmpg.htm>

## **Medicare & Medicaid Resources**

- Medicaid State Plans  
[www.hcfa.gov/medicaid/stateplan/default.asp](http://www.hcfa.gov/medicaid/stateplan/default.asp)

- California Medicare Resources\*\*  
<http://www.calmedicare.org/view.cfm?section=8&itemID=4461>
- Medi-Cal or Healthy Families  
<http://216.239.35.100/search?q=cache:bvVpfNiWg1MC:www.4children.org/pdf/501heale.pdf+health+advocacy+Los+Angeles&hl=en&ie=UTF-8>
- Medicare/Medicaid fraud and abuse\*\*  
<http://justwhisper.com/>
- Medicaid  
<http://www.healthlaw.org/medicaid.shtml>
- Health Care Financing Administration (HCFA)  
<http://www.hcfa.gov/medicaid/medicaid.htm>
- Medicaid Clearinghouse  
<http://www.familiesusa.org/>
- The Urban Institute  
<http://www.urban.org/medicaid>
- Official Medicare Website  
<http://www.medicare.gov/>
- Consumer Union Medicare Page  
<http://www.consunion.org/health/i-medicare.htm>
- Center for Medicare Advocacy  
<http://www.medicareadvocacy.org/>
- Medicare Payment Advisory Commission (MedPAC)  
<http://www.medpac.gov/>
- The Commonwealth Fund Program on Medicare's Future  
<http://www.cmwf.org/publist/index.asp - future>
- Medi-Cal Policy Institute  
<http://www.medi-cal.org/>
- Families USA's Medicaid Clearinghouse  
<http://www.familiesusa.org/>
- SCHIP Approved Plans  
[www.hcfa.gov/init/chpa-map.htm](http://www.hcfa.gov/init/chpa-map.htm)
- CMS Letters to State Medicaid Directors  
[www.hcfa.gov/medicaid/letters/default.htm](http://www.hcfa.gov/medicaid/letters/default.htm)
- CMS' State Medicaid Manual  
[www.hcfa.gov/pubforms/pub45/pub\\_45.htm](http://www.hcfa.gov/pubforms/pub45/pub_45.htm)
- Understanding Medicaid Home and Community Services: A Primer  
<http://aspe.hhs.gov/daltcp/reports/primer.htm>

- Title V Information System  
[www.mchdata.net/](http://www.mchdata.net/)
- HIPAA Information  
[www.hcfa.gov/medicaid/hipaa/default.asp](http://www.hcfa.gov/medicaid/hipaa/default.asp)
- Directory of Medicaid and MR/DD/Waivers by State  
[www.geocities.com/HotSprings/Villa/1029/medicaid.html](http://www.geocities.com/HotSprings/Villa/1029/medicaid.html)

## **Minority Health Resources**

- Asian and Pacific Islander American Health Forum – APIA HF  
<http://www.apiahf.org/>
- The primary objective of REACH 2010 is to assist communities in mobilizing and organizing resources in support of effective and sustainable programs that help to eliminate health disparities experienced by racial and ethnic minorities\*\*  
<http://www.chc-inc.org/REACH2010/>
- Racial/Cultural Issues  
<http://www.healthlaw.org/race.shtml>
- The Initiative to Eliminate Racial and Ethnic Disparities in Health  
<http://raceandhealth.hhs.gov/>
- Minority Health Project  
<http://www.minority.unc.edu/>
- Office of Minority Health Resource Center  
<http://www.omhrc.gov/>
- Diversity RX  
<http://www.diversityrx.org/>
- Race, Health Care and the Law  
<http://www.udayton.edu/~health/>

## **Reproductive Health Resources**

- National Center for Education in Maternal and Child Health\*\*  
<http://www.ncemch.org/>
- Reproductive Health  
<http://www.healthlaw.org/repro.shtml>
- ACLU Reproductive Freedom Project  
<http://www.aclu.org/issues/reproduct/hmrr.html>
- Center for Reproductive Law and Policy  
<http://www.crlp.org/>

- National Abortion and Reproductive Rights Action League (NARAL)  
<http://www.naral.org/>
- National Women's Health Information Center  
<http://www.4woman.gov/>
- Planned Parenthood Federation of America  
<http://www.plannedparenthood.org/>

## **Other Health Related Resources**

- Allhealth.com  
<http://www.allhealth.com>
- CBS Health Watch  
<http://www.cbshealthwatch.com>
- Onhealth  
<http://www.onhealth.com>
- STD and Gay youth\*\*  
<http://www.youthresource.com/>
- American Medical Association\*\*  
<http://www.ama-assn.org/>
- National Center for Chronic Disease Prevention and Health Promotion\*\*  
<http://www.cdc.gov/nccdphp/>
- The National Center on Addition and Substance Abuse at Columbia University\*\*  
<http://www.casacolumbia.org/>
- The U.S. Departments of Education's Higher Education Center for Alcohol and Other Drug Prevention\*\*  
<http://www.edc.org/hec/>
- The Foundation for Taxpayer & Consumer Rights (FTCR)  
<http://www.consumerwatchdog.org/>
- Young Women and Smoking\*\*  
<http://www.inwat.org/young.htm>
- The National Council on Alcoholism and Drug Dependence\*\*  
<http://www.ncadd.org/>
- National Institute on Drug Abuse\*\*  
<http://www.drugabuse.gov/NIDAHome.html>
- Health Finder\*\*  
<http://www.healthfinder.gov/>
- Prevention Research Institute\*\*  
<http://www.askpri.org/>

- WebMD  
<http://www.webmd.com>

## **Media Advocacy**

- Media “How-To” Books on Media Advocacy  
<http://www.causecommunications.com/diy/howtobooks.html>
- References and Resources for Media Advocacy  
<http://www.edc.org/hec/socialnorms/mediaadvocacy/>
- Online advocacy tool  
<http://capitoladvantage.com/h2/>
- National Media Education Campaign  
<http://www.aap.org/advocacy/mmcamp.htm>
- Resources for Health and the Mass Media  
<http://www.health.usyd.edu.au/resources/mchbib/advocacy.html>  
<http://www.health.usyd.edu.au/resources/mchbib/media-e.html>
- Institute for Public Health  
<http://www.healthadvocacy.org/default.htm>
- Federal Communication Network  
<http://www.fcn.gov/>
- Media contact list, FAIR.  
<http://www.fair.org/media-contact-list.html>
- Infectious Disease Association of California (IDAC)  
<http://www.idac.org/>
- Emerging Infectious Diseases, CDD  
<http://www.cdc.gov/ncidod/eid/>
- Sexually Transmitted Diseases  
[http://edcenter.med.cornell.edu/Pathophysiology\\_Cases/STDs/STD\\_TOC.html](http://edcenter.med.cornell.edu/Pathophysiology_Cases/STDs/STD_TOC.html)
- Links on Infectious Diseases  
<http://www.fas.org/promed/promdwww.html>
- National Public Health Performance Standards Program State public Health System Performance Assessment (Article, Dec 2001)  
<http://www.apha.org/ppp/shipmain/StateFinal.PDF>

## **Violence**

- National Coalition Against Domestic Violence  
[www.ncadv.org](http://www.ncadv.org)
- Family Violence Prevention Fund  
<http://endabuse.org/>

- National Network to End Domestic Violence  
[www.nnedv.org](http://www.nnedv.org)
- Center for the Prevention of Sexual and Domestic Violence  
[www.cpsdv.org](http://www.cpsdv.org)
- Asian Task Force Against Domestic Violence, Inc.  
[www.atask.org](http://www.atask.org)

## **Participatory Research and Evaluation**

- UCSF: Center for Health Professionals  
<http://futurehealth.ucsf.edu/ccph/commbas.html>
- University of Kansas – community tool box  
<http://ctb.ukans.edu>
- Loka Institute, UMASS-Amherst – Exec. Summary of Community Based research in the US  
<http://www.loka.org/CRN/summary.htm>
- Developing an Evidence Based Guide to Community Preventive Services  
<http://www.loka.org/CRN/summary.htm>
- Eldis – Participatory Monitoring and Evaluation  
<http://www.ids.ac.uk/eldis/hot/pme.htm>
- Harvard Family Research Project – articles on participatory research  
<http://www.gse.harvard.edu/~hfrp/eval/issue2/>
- USAID – Tips for conducting cbppr  
[http://www.dec.org/pdf\\_docs/pnabs539.pdf](http://www.dec.org/pdf_docs/pnabs539.pdf)  
'Partnerships for the Public' borrowed heavily from this article
- Kellogg Foundation – how-to guidebook on participatory evaluation  
<http://www.wkkf.org/pubs/Pub770.pdf>